Submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) Inquiry into Supported Independent Living

Cecile Sullivan Elder
Executive Officer, Family Advocacy
cecile@family-advocacy.com

Leanne Varga
Systemic Advocate
leanne@family-advocacy.com

Family Advocacy
(02) 9869 0866
Suite 704, 88-90 George Street,
Hornsby, NSW 2077, Australia

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TERMS OF REFERENCE:

As part of the committee's role to inquire into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS), the committee will inquire into and report on Supported Independent Living (SIL), with particular reference to:

A. the approval process for access to SIL;

C. the funding of SIL;

D. any related issues.

Overview

Family Advocacy provides advice and support to families so they can advocate with or on behalf of their family member with developmental disability (hereinafter disability). Our goal is to advance and protect the rights of people with disability so that meaningful lives can be enjoyed by experiencing the same opportunities and living conditions as the majority of Australians. Our work includes representing the rights and interests of a person with disability to Government regarding legislation, policy, funding, monitoring and practice in areas that impact detrimentally on people with disability.

Family Advocacy was founded and is governed by families of people with disability and is funded by the New South Wales (NSW) and Federal governments. One of our initiatives, Resourcing Inclusive Communities, aims to assist families to develop skills and confidence so that they can support their family member to have more choice and control over decisions and supports that facilitate individualised and normative lifestyles. This includes making the most of emerging opportunities for self-directing supports and to use creative and innovative models of support through individualised funding.

In this way, we believe our purview lies in alignment with the overall objectives of the National Disability Insurance Scheme (NDIS) Act (1 July 2013), with a similar aim to provide transformational benefits to the lives of people with a disability. Putting the person with disability at the centre of the decision making with regard to arrangements and supports is a critical component of this.

Family Advocacy appreciates the opportunity to provide input to the Joint Standing Committee on the NDIS on its Inquiry into “NDIS Planning”. This submission is based on a survey of 56 people with disability and/or their family members. It is shaped by the accumulated knowledge of families experience that spans nearly 30 years in advocating for supports, enhanced policies and practices that value the lives of people with disability. Family Advocacy has connected with many people across NSW throughout the roll out of the NDIS. For confidentiality reasons, the names of the parent and their child with disability have been purposefully changed. For ease of reference, we have used the same alphabetical numbering system as per the Terms of Reference.

Family Advocacy would welcome the opportunity to provide evidence should there be an upcoming hearing in Sydney.

Executive Summary

Family Advocacy has made the following key recommendations:

Recommendation 1:	*The Joint Standing Committee on the NDIS recommend State and Territory governments provide funding in perpetuity for disability advocacy.*
Recommendation 2:	*The NDIA address the need for cultural change that enables staff to be genuinely person-centred, and support individualised independent living.*
Recommendation 3:	*The need for the Planners to respect the family as a natural authority in the life of the person with disability.*
Recommendation 4:	*The Planner to have a flexible approach rather than a one size fits all approach.*

Introduction

The NDIS is underpinned by the broader vision of a fully inclusive society where a person with disability has more choice and control in their life. Supported Independent Living (SIL) funding supports the person with daily tasks and to develop the skills of an individual to live as independently as possible. These are the supports provided to a person with disability in their home, regardless of property ownership, and this can be in a shared or individual arrangement.

We strongly support the notion that a person with disability should be supported to live independently and should be authentically included in the community, as codified by Article 19 of the United Nations Convention on the Rights of Persons with Disability. Unfortunately, there appears to be a significant disconnect between policy and practice within the NDIA.

Results from our survey and our experience with supporting families has shown that the NDIS Supported Independent Living (SIL) funding process is highly flawed and presumes all people with disability will live in segregated group homes. The current process completely negates individual choices in living arrangement as the SIL process funds people with disability on "capacity to share" with others with disability. A more nuanced approach is required to support individualised living arrangements, including more scope in sharing with flatmates that do not have a disability and other models that support the notion of person living in a home of their own versus a segregated accommodation placement.

The need for advocacy

Before we provide input specifically in relation to the Terms of Reference, we must highlight the absolute necessity of advocacy in the NDIS Planning process. The introduction of the NDIS has created significant change in the sector and for people with disability. As a result, the current problems within NDIS from a planning perspective have resulted in a greater need for independent disability advocacy.

Our families have expressed shock that so much advocacy is required on their part under this new system. They want the NDIS to be a success but have found the increased need for advocacy due to many barriers within the current system, which are discussed below. Families want to be heard in relation to these systemic issues, but are frustrated and exhausted.

On an individual level, our advocacy, representation and information has provided essential supports to enable people with disability (and their family representative) to fully participate in the NDIS and to be included in the community. This inquiry is one of many where we, and other disability advocacy organisations, have provided submissions to State and Federal governments as well as directly to the National Disability Insurance Agency (NDIA). Systemic advocacy provides an alarm bell to warn where there are significant issues to enable the NDIA to respond to failures in the system, prevent unnecessary cost, time wasting, and avoid problems before they blow up into preventable tragedies. Most importantly bringing to the forefront the significant implications that current processes and practices are having directly on the people whom the the system is there to support. The person with disability.

Disability advocacy is distinct from the functions funded under NDIS, including the Information, Linkages and Capacity Building (ILC) component of the NDIS. ILC funding does not replace the need for funding disability advocacy. The Government's own guidelines state that "we will not fund individual or systemic advocacy in ILC."

With the introduction of NDIS, the NSW Government decided to redirect all its NSW disability funding to the Federal Government, including the funds for disability advocacy, representation and information organisations. After a concerted campaign by people with disability and community groups, in early April 2018, the NSW Government announced interim funding for disability advocacy support of $13 million per annum but only until June 2020.

Without secure long-term funding commitments from the NSW Government, the 10% of people with disability provided with an NDIS funded plan, won' t have access to an independent advocate to help them navigate the fledgling NDIS system. Disability services providers, the NSW Ombudsman and the Productivity Commission have noted the crucial role of funded disability advocacy support, particularly with the introduction of the NDIS. For the 90% of people with disability not receiving NDIS funding, the loss of disability advocacy will mean an even greater gap in access to supports and being included in their community.

State Governments have a clear responsibility for ongoing funding to ensure that people with a disability will always be able to turn to local, independent advocate when they need them. The Federal Government, through its Assistant Minister for Disability, and the Minister for Social Services, has made it clear that state governments need to maintain ongoing funding for disability advocacy.

Independent reports such as the 2011 Productivity Commission Inquiry into Disability Care and Support noted that advocacy functions and their funding "should lie outside the NDIS, reflecting the potential conflict of interest that would arise were the NDIS to fund advocacy bodies whose role was to challenge the disability funding system overseen by NDIS. Current funding arrangements through state and territory governments should continue." In 2017, the Productivity Commission again confirmed that State Governments are responsible for funding disability advocacy, separately to any handover of disability funding under arrangements for NDIS.

Family Advocacy calls on the Joint Standing Committee on the NDIS to make a recommendation as part of this Inquiry into NDIS Planning that all State and Territory governments provide funding in perpetuity for disability advocacy, representation and information services for people with disability.

Recommendations

Recommendation 1: The Joint Standing Committee on the NDIS recommend State and Territory governments provide funding in perpetuity for disability advocacy.

(a) The approval process for access to SIL

> *Our son's goal is to live independently. He lives on his own in a granny flat but has only received only 50% (approximately) of the funds required for 5 days per week of independent living with support. We didn't get any proper explanation about why our son has only received 50% of the required support funds.*

> *SIL Funding is insufficient. NDIA approval processes are rigid, requiring a quote from the provider so it is difficult to change service provider. NDIA approval processes are too slow. It's impossible to get an alternative quote for SIL so it's impossible to even consider changing provider.*

> *Constant negotiation/advocacy with agency which is exhausting. A "group home" mentality, rather than person centred. Not been allowed to plan manage or self manage in a shared house setting....where this has been done successfully previously. Unable to use SIL outside of house setting ....e.g. hospital stays, medical appointments in the city (we are regional), supporting new experiences outside of house. Agency prefers SIL funding over CORE. Say no more!!*

From a policy perspective, the NDIA assumes a person-centred approach that aims to ensure the person's needs and preferences are a driving force behind decisions and planning that occurs in relation to them. However, feedback from people with disability and/or their family member reveals that in the approval process for access to SIL, planners have a strong tendency to want to fund group segregated setting over individual support and are attempting to be very pervasive to this end. This reflects the mindset of the outdated and traditional approaches to institutional supports for people with disability in which the NDIA purports to want to move away from.

The above situation has the effect of forcing people with disability to share accommodation with another person with disability or the family has to self-fund the difference. This is clearly not a person-centred approach. A common experience of families was that when more normative support arrangements that were individualised and connected to community were sought, it was common for planners to continue to strongly push the segregated options. Even when families felt that a strong case for funding for their family member had been expressed and documents were presented at the meeting, the plan would still come back representing segregated arrangements. This was very concerning for many families and life limiting for the person with disability.

Recommendation 2: The NDIA address the need for cultural change for staff to be genuinely person-centred, and support individualised independent living..

> *Need to be flexible funding options. Not everyone with a disability lives in group homes.*

With listening to families, the NDIS needs to ensure that it is flexible to allow for the fact that one size does not fit all and to allow for creative support arrangements outside of the traditional approaches used historically for many people.

This will take intentional effort from the NDIA in relation to rethinking its processes and ensuring that contemporary quality training is provided to its employees. This approach is the premise of the disability sector changes so it is about recalibrating the intent of the scheme to the current reality.

Another area of concern is around the choice of NDIS funding management. A number of families have shared that despite wanting to self-manage the NDIS funds as a nominee, they have had to be agency managed. The person with the disability and nominee should have the right to choose how they manage their funds.

Recommendation 3: The need for the Planners to respect the family as a natural authority in the person with disability life.

(c) The funding of SIL

The examples below are very concerning and show the lack of transparency and accountability of service providers in relation to SIL funding. Better processes need to be put in place to provide the person with disability and their family information about how their funding is being allocated.

> *My son at present is transitioning into group home for the first time. The SIL has been allocated (end of June 2019) to Service Provider. Since funds have been allocated to the service provider, they commenced drawing on the weekly amount although he has not fully transitioned into the group home. As SIL is agency managed, I have no access to funds directly but the service provider has without a service agreement signed.*

> *Huge gaps in what is promised and in reality what really happens. Staff regularly do NOT follow support plans for independent living skills. Huge disappointment on so many levels. Provider keeps changing supports regarding what they will provide. When individual support was included in the SIL, if they were short on staff carer was not replaced.*

> *We wanted to self-manage but were told we could not. I feel that the agency believes that it is their money ... not our son's funding. It still feels very institutionalised and rigid. We are just hanging in there as other options are limited. The agency will not show a breakdown or quote that is used to obtain SIL funding for our son. The agency is not interested at all in us plan managing our son's funding in the share house, and has stated that SIL is not "for us to worry about" therefore leaving us with little trust as we are not shown figures.*

> *Disappointing, frustrating, non transparency by agency, too regulated, not flexible and overall a let down compared to previous individualised funding under Living Life my Way. The NDIA seems to have taken a step backwards into group home mentality with SIL regulations, which supports/encourages congregation and isolation for many people...STILL!! I think the SIL funding is good and on target with our son's complex needs, it is more the Service Providers' mode of delivery that has been allowed to stay in the dark ages.*

(d) Any related issues

Recommendation 3: The need for the Planners to respect the family as a natural authority in the life of the person with disability.

Family is the natural authority of the person with disability

The families' experiences we have shared highlight the importance of the NDIA recognising that the family is the natural authority for their family member with developmental disability. Families ought to be recognised as having credibility and experience in understanding what are the most optimal support arrangements for their family member with disability. And importantly understanding what their family members' preferences are. Indeed, the acknowledgement and respect of the role of family in the lives of people with disability is one of the general principles listed to guide the actions of the NDIA.

Recommendation 4: The Planner to have a flexible approach rather than a one size fits all approach.

Conclusion

This submission has clearly illustrated that people with disability need the NDIS SIL funding process to be a genuinely person-centred and flexible in its approach, valuing and respecting how the person with disability chooses to live. Rather than home ownership, living alone or sharing a small household with others they choose as a right, the current outdated approach of SIL funding perpetuates a life trajectory of eventual acceptance of the one living arrangement they perceived open to them - group homes.

Persisting with this institutionalised mentality continues to reinforce the stereotype that people with disability should experience life on the margins of community life and can only reside with other people with disability. It also does little to extend friendship pools beyond those that are dominated by family and/or support workers. Hence, taking away the opportunity for the person with disability of the opportunity to live a typical and meaningful life.

As previously expressed, the need for advocacy has never been greater. Family Advocacy wants SIL to be a success so a person with disability can live independently with people of their choosing. The NDIA must provide the due diligence required to overcome the old mindsets and systemic barriers discussed in this submission, particularly in supporting the choice to self-manage SIL funds.

Each family has its own method of operating and each person with disability in their life has their own support needs that need to be considered. The family is best placed to make these decisions as they are for their other children without disability, and any system changes should have this at the cornerstone of its design.

Whilst there have been significant problems, they are not insurmountable as long as the NDIA is prepared to listen to the feedback from families regarding the direct impact that current policy and practice have concerning the SIL funding. We hope the Joint Standing Committee on the NDIS concur with our recommendations, and they are implemented by the NDIA.